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What Black Women Should Know About Lupus

Signs of Lupus

1. Red rash or color change on face, often in the shape of a butterfly across the bridge of the nose
2. Painful or swollen joints
3. Unexplained fever
4. Chest pain with breathing
5. Unusual loss of hair
6. Pale or purple fingers or toes from cold or stress
7. Sensitivity to the sun
8. Low blood count

These signs are more important when they occur together.

For further information, see your doctor or health clinic and contact your local chapter of the following organizations:

The Lupus Foundation of America, Inc.
4 Research Place
Suite 180
Rockville, Maryland 20850-3226
(800) 558-0121

The American Lupus Society
3914 Del Amo Blvd.
Suite 922
Torrance, California 90503
(800) 331-1802

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service National Institutes of Health
Task Force on Lupus in High Risk Populations

HEALTH WATCH: BLACK WOMEN AND LUPUS

Did you know that lupus is a disease that occurs more frequently in young black women than in any other group? Lupus can be serious, but with early detection and good treatment, most people with lupus can lead a normal life.

Considering these facts, it is important that Black Americans, particularly young, black women know about lupus, its symptoms, and its treatment.

Lupus is a disease that can affect many parts of the body. In lupus, something goes wrong with the body's immune system, and this powerful protective system is no longer able to defend the body against illness. Instead, the immune system attacks healthy tissues.

There are three types of lupus. The most serious of these is systemic lupus erythematosus which may harm the skin, joints, kidneys, brain, lungs, and heart. Discoid or cutaneous lupus mainly affects the skin. Lupus caused by medications, or drug-induced lupus, goes away when the medication is stopped.

How can you tell if you or someone you know has lupus? The signs of lupus differ from one person to another. Some people have many signs of the disease. Others have just a few. The common signs of lupus are:

- Red rash or color change on the face, often in the shape of a butterfly across the bridge of the nose.
- Painful or swollen joints.
- Unexplained fever.
- Chest pain with breathing.
- Unusual loss of hair.
- Pale or purple fingers or toes from cold or stress.
- Sensitivity to the sun.
- Low blood count.

These signs are more important when they occur together.

Only a doctor can diagnose lupus. If you think you or someone you know has lupus, see a doctor right away. The doctor will perform an examination and test for the disease.

The cause of lupus is unknown. However, research doctors have learned a great deal about lupus and are studying new ways to treat and, hopefully, prevent the disease.

FOR MORE INFORMATION call the Lupus Foundation of America, at (800) 558-0121 or The American Lupus Society at (800) 331-1802 or write the Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892.

Facts About Lupus and Black Women

Who Gets Lupus?

- Lupus is a serious health problem that mainly affects young women. Most people with lupus first get it as teenagers or as young adults. People of all races may get lupus. However, black women are three times more likely to develop lupus than white women.
- You cannot catch lupus from someone else. You cannot give lupus to someone else. Lupus is not cancer. It is not AIDS.

What Is Lupus?

- In lupus, something goes wrong with the body's immune system, and this powerful protective system is no longer able to defend the body against illness. Lupus may affect the joints, the skin, the kidneys, the lungs, the heart, or the brain.

There Are Three Types of Lupus:

- Systemic lupus erythematosus the most serious form of lupus, which may harm the skin, joints, kidneys, brain, lungs, and heart.
- Lupus that mainly affects the skin (discoid or cutaneous lupus).
- Lupus caused by medications (drug-induced lupus), which goes away when the medication is stopped.

Common Signs of Systemic Lupus:

- Red rash or color change on the face, often in the shape of a butterfly across the bridge of the nose.
- Painful or swollen joints.
- Unexplained fever.
- Chest pain with breathing.
- Unusual loss of hair.

- Pale or purple fingers or toes from cold or stress.
- Sensitivity to the sun.
- Low blood count.

These signs are more important when they occur together.

Other signs of lupus can include mouth sores, unexplained fits or convulsions, hallucinations, or depression; repeated miscarriages; and unexplained kidney problems.

Signs of lupus tend to come and go. There are times when the disease quiets down or goes into remission. At other times lupus flares up or becomes active.

Diagnosis and Treatment:

- Only a doctor can diagnose lupus. If you think you or someone you know has lupus, see a doctor right away. The doctor will perform an examination and test for the disease.
- The doctor may prescribe a variety of medications for the lupus patient.
- If you have lupus, you may need extra rest. Try to avoid stressful situations, and stay out of the sun. Some people should avoid sunlight because it may worsen the disease.
- We do not know what causes lupus, but researchers are looking for a cure. Researchers also are improving ways to detect and treat the disease.

For More Information:

- Call the **Lupus Foundation of America, Inc.**, at (800) 558-0121 or **The American Lupus Society** at (800) 331-1802 or write the **Task Force on Lupus in High Risk Populations**, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892.

Prepared by the
NIAMS Task Force on Lupus in High Risk Populations
National Institute of Arthritis and
Musculoskeletal and Skin Diseases

NIAMS, a part of the National Institutes of Health, leads and coordinates the Federal biomedical research efforts in lupus.

SELECTED LUPUS PATIENT EDUCATION MATERIALS

Pamphlets, Brochures, and Books

Facts About Lupus: Living Well With Lupus.
Rockville, MD: Lupus Foundation of America, Inc. 1988. 10 p.
Available from the Lupus Foundation of America, Inc., 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292. (800) 558-0121. PRICE: $7.00 per 100.

This pamphlet describes the characteristics and the different types of lupus and provides practical advice about living with lupus. Specific guidelines are included concerning the importance of nutrition (dietary do's and don'ts), exercise, looking good, and living a wholesome life with respect to family, friends, medical care, and other lifestyle factors.

Facts About Lupus: Pregnancy and Lupus.
Rockville, MD: Lupus Foundation of America, Inc. 1990. 8 p.
Available from the Lupus Foundation of America, Inc., 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292. (800) 558-0121. PRICE: $7.00 per 100.

Since lupus primarily affects women of childbearing years, pregnancy often is a crucial concern. Half of lupus pregnancies are completely normal, and one-fourth result in normal babies delivered prematurely. The remaining one-fourth of pregnancies are affected by miscarriages or death of the baby. This brochure describes the risks and guidelines to consider when contemplating pregnancy. Recent studies indicate that abnormalities that occur in lupus pregnancies are due to the pregnancy itself and not to lupus. Information is included about proper monitoring for women, medication precautions, treatment with prednisone, incidences of babies born with the disease, breast feeding, and contraception.

Facts About Lupus: What is Lupus?
Rockville, MD: Lupus Foundation of America, Inc. 1988. 8 p.
Available from the Lupus Foundation of America, Inc., 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292. (800) 558-0121. PRICE: $7.00 per 100.

In this pamphlet, the symptoms, characteristics, and diagnosis of lupus are discussed. The different types of lupus and the people who are at greatest risk for the disorder are described. Information also is included concerning the causes of a lupus episode.

Facts About Lupus: What is Vasculitis?

Rockville, MD: Lupus Foundation of America, Inc. 1988. 12 p.

Available from the Lupus Foundation of America, Inc., 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292. (800) 558-0121. PRICE: $7.00 per 100.

This pamphlet describes the characteristics of vasculitis; its symptoms, diagnosis, and treatment; what causes it; and diseases associated with vasculitis, including lupus. Guidelines for consulting a physician and information about the outcome of vasculitis also are included.

Lupus: A Guide for Patients.

Hughes, G.R.V.

Torrance, CA: American Lupus Society. 25 p.

Available from The American Lupus Society, 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (213) 542-8891. (800) 332-1802. PRICE: $3.75.

This pamphlet was written by a consulting physician at the Lupus Clinic at St. Thomas' Hospital in London. The author discusses all major aspects of the illness, including its history, clinical features, various forms, testing, treatment, medication, research, and prognosis.

Lupus and Women of Color.

San Jose, CA: Lupus Foundation of America, Bay Area Chapter. 6 p.

Available from the Lupus Foundation of America, Bay Area Chapter, 2635 North First Street, Suite 206, San Jose, CA 95134. (408) 954-8600. PRICE: Single copies free.

This brochure briefly explains the symptoms and characteristics of SLE. A checklist is provided for people to determine if they may have one or more of the symptoms. Information is included on the activities of the Bay Area Lupus Foundation. This brochure is also available in Spanish and Vietnamese.

Lupus Erythematosus: A Handbook for Physicians, Patients, and Their Families. Second Edition.

Carr, R.I.

Washington, D.C.: Lupus Foundation of America, Inc. 1986. 60 p.

Available from the Lupus Foundation of America, Inc., 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292. (800) 558-0121. PRICE: $3.00.

This comprehensive booklet describes lupus, its relevance, symptoms, etiology, diagnosis, treatment modalities, and future prognosis. New approaches to therapy that are currently being investigated are discussed. The goals of the Lupus Foundation and the

medical research funded by the National Institutes of Health are outlined. A reading list categorized into general, health professionals, physicians, and research scientists is appended. Also available in Spanish.

Lupus Words & Terms.
St. Clair Shores, MI: Michigan Lupus Foundation. 1983. 6 p.
Available from the Michigan Lupus Foundation, 26202 Harper Avenue, St. Clair Shores, MI 48081. (313) 775-8310. PRICE: Single copies free.

This pamphlet provides 114 definitions of medical words and terms that patients may encounter while reading about lupus erythematosus.

Managing Your Pain Effectively.
Montreal, Quebec, Canada: Lupus Society of Quebec. 20 p.
Available from the Lupus Society of Quebec, 3575 St. Laurent Boulevard, Suite 242, Montreal, Quebec, Canada H2X 2T7. (514) 849-0955. PRICE: Call for price information.

This booklet is intended to help patients develop a plan of action for handling their pain. The different types of pain people experience and various pain management techniques are described. The booklet provides a daily log for patients to record their pain patterns. This daily log can then be used by patients and their doctors and nurses to develop a personalized plan for pain management.

Coping with Lupus: A Guide to Living with Lupus for You and Your Family.
Phillips, R.H.
New York, NY: Avery Publishing Group. 1984. 244 p.
Available from Avery Publishing Group, 120 Old Broadway, Garden City Park, NY 11040. (516) 741-2155. (800) 548-5757. PRICE: $7.95.

This practical handbook, written in a relaxed, informal style by a practicing psychologist, describes strategies and techniques aimed to improve the quality of life of lupus patients and their families. Topics addressed include how to deal with different emotional reactions, how to manage stress, the physical symptoms of lupus and how to handle them, sexual relations, interaction with others, and how to cope with financial problems. The book is divided into five sections: Lupus - Some Background; Your Emotions; Changes In General Life-Style; Interacting With Other People; and Living with Someone Who Has Lupus. An appendix lists suggestions for further reading and the addresses of the Lupus Foundation of America and the American Lupus Society.

Lupus and You.

Reinertsen, J.L.

Minneapolis, MN: Park Nicollet Medical Foundation. 1986. 32 pages.

Available from the Park Nicollet Medical Foundation, Communications Department, 5000 West 39th Street, Minneapolis, MN 55416. PRICE: $2.00.

This booklet, written by a noted rheumatologist, is intended to help people with SLE understand what lupus is, what effects it might have on their lives, and what they can do to help themselves and their doctors in the management of the disease. Possible causes, symptoms, and diagnosis of lupus are described. Since successful management of lupus may involve changes in attitude, diet, and lifestyle, emphasis is placed on a positive and realistic mental attitude, protection from the sun, dealing with fatigue, and adjusting to medications and their possible side effects. Keeping drug records and carefully monitoring for signs of drug reactions or complications are recommended. A glossary of lupus-related terms is included.

Audiovisuals and Posters

Butterfly.

Washington, D.C.: Lupus Foundation of America, Inc.

14 x 18-inch poster or 15 1/2 x 25 1/2-inch poster.

PRICE: .85/each

Available from the Lupus Foundation of America, Inc., 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292. (800) 558-0121.

This brown and white poster displays a butterfly, the symbol used by the Lupus Foundation of America, Inc., and a caption beneath it reading: "Lupus Erythematosus: It may be hard to pronounce but it is even harder to live with."

Lupus Disease: Its Effect on Women.

National Public Radio, Horizons Series. 1988. Audiocassette.

Available from National Public Radio Cassettes, P.O. Box 55417, Madison, WI 53705. (800) 235-8273. PRICE: $12.95.

In this audiocassette, lupus patients discuss the symptoms and complications of their disease, and the daily struggles they must meet to live with lupus.

Lupus: Insights, Emotions, Encouragement.
Gill, W.; Gill, E. (Producers/Writers)
Columbus, OH: Columbus Chapter of the Lupus Foundation of America, Inc.
1987. 1/2-inch VHS.
Available from the Columbus Chapter of the Lupus Foundation of America, Inc., 5180 East Main, Columbus, OH 43213. (614) 267-0811.

This video, featuring discussions with doctors, nurses, patients, and families and friends of patients, focuses on strategies for living and building constructive relationships. Also discussed are signs and symptoms of lupus, how the disease changes the patient's life, coping with those changes, medication, reactions of families and friends, and the role of support groups.

Lupus: The Great Imposter.
Alexandria, VA: Lupus Foundation of Greater Washington, Inc.
1/2-inch VHS and 3/4-inch U-Matic. 14 minutes.
Available from the Lupus Foundation of Greater Washington, 6210 North Kings Highway, 2B, Alexandria, VA 22303. (703) 660-6523. PRICE: $30.00 for VHS format, $45.00 for U-Matic format.

In this video, several individuals who suffer from lupus are introduced along with their friends and families. Viewers are informed about the basic nature of the disease and its effect upon the lives of those who suffer from it. The video also features physicians who discuss the disease, the state of research into finding a cure, and the kind of support the ongoing research effort requires. This film was awarded a certificate of merit from the American Medical Writers Association and a Golden Eagle Award from The Council on International Nontheatrical Events, both in 1987.

SLE: **The Great Deceiver.**
San Jose, CA: Lupus Foundation of America, Bay Area Chapter. 1986.
3/4-inch U-Matic, 1/2-inch VHS or Beta-Max II videocassette, or
110 35mm. slides with audiocassette (30 min.), color.
Available from Lupus Foundation of America, Bay Area Chapter, 2635 North First Street, Suite 206, San Jose, CA 95134. (408) 954-8600. PRICE: $50 (videocassette, purchase), $125 (slide/tape, purchase), $25 rental fee, applicable to purchase. Postage: $6 for slide/tape, $4 for 3/4-inch video, 3 for 1/2-inch video.

This two-part program was produced primarily for newly diagnosed lupus patients and their families. Patients need to be informed about the medical facts, methods of treatment, potential problems, how they can better manage their disease, and how to build better communication within their family and with others who play an important role in their lives. Part 1, Signs and Symptoms, presents an overview of the pathophysiology of lupus, including a simplified description of how the immune system malfunctions in lupus

patients. A typical lupus patient describes what it is like to be diagnosed as having lupus. The attending physician responds by identifying the methods used in diagnosis, including the A.R.A. criteria, laboratory tests, clinical findings, and history. Symptoms that are not included in the specified criteria are also discussed. Part 2, Treatment and Management, concerns daily living with lupus. Patients learn ways of monitoring the course of their own disease, effective methods of controlling the disease, relating to the members of their family and their own physicians, and ways of modifying their lifestyle to accommodate this disease. This presentation is also suitable for nurses and other health professionals who would like to learn more about lupus and how it affects patients and their families.

Source: National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse. Lupus: Patient Education Materials. An Annotated Bibliography 1990.

Lupus in High Risk Populations

THIS KIT CONTAINS facts and information you can use to promote awareness of lupus among black women in your community.

Feel free to adapt the kit to meet your needs. We designed the materials to be copied and distributed widely throughout your local networks. Please let us know what you think of the kit and how your organization observed National Lupus Awareness Month, or how you plan to use the materials at any time during the year. A response card is enclosed for your convenience.

The materials can be used in settings such as health fairs, clinics or hospitals, workplaces, churches, retail outlets, libraries, and recreation centers. Enclosed you will find:

- Memorandum to Colleagues
- Information on NIAMS and the Task Force on Lupus in High Risk Populations
- List of Task Force Members
- Facts About Lupus and Black Women
- Information Booklet--"What Black Women Should Know About Lupus"
- Newsletter Article--"Health Watch: Black Women and Lupus"
- A "fill-in-the blanks" press release
- Ideas on how to work with local media
- PSA's for use by radio announcers
- Suggested activities
- Sources of information on lupus
- List of selected patient education materials
- Poster
- Camera-Ready Artwork: booklet, poster, butterfly logo, stationery
- Response card
- Order form

Lupus in High Risk Populations

TO: Colleagues

FROM: The Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institutes of Health

SUBJECT: National Lupus Awareness Month, October 1991

You can help raise awareness in your community about lupus in young black women and encourage them to see a doctor if they have symptoms of the disease.

Lupus is a serious health problem of special concern to young black women of childbearing age. Although people of all races may get lupus, it has a three times higher incidence, prevalence, and mortality in black women than in white women. Lupus is often hard to diagnose because it mimics many other diseases.

Many in the black community have never heard of lupus, and it often goes undiagnosed until serious complications arise. The disease may damage the joints, skin, kidneys, lungs, heart, or brain. However, the good news is that with the correct medicine and taking care of themselves most lupus patients can hold a job, have children, and lead a full life.

This year during Lupus Awareness Month, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) will highlight lupus and the importance of early diagnosis.

Make your community a more informed one by helping us get the word out about lupus. The enclosed Lupus Resource Kit was designed to assist organizations in setting up local programs and distributing materials to raise awareness about lupus. This kit was developed by the NIAMS Task Force on Lupus in High Risk Populations. The kit contains reproducible educational and media materials. In addition, you'll find an information booklet entitled "What Black Women Should Know About Lupus," which answers questions concerning the causes of lupus, its different forms, and its symptoms, diagnosis, and treatment.

Please take time to read these materials. We encourage you to use them as they are or to adapt them to your needs.

If you would like additional materials, please contact the Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892, (301) 495-4484, FAX (301) 587-4352. We welcome your comments on this effort and also would be interested in hearing about how these materials are used.

THE NIAMS AND THE TASK FORCE ON LUPUS IN HIGH RISK POPULATIONS

National Institute of Arthritis and
Musculoskeletal and Skin Diseases
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892
(301) 495-4484

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a component of the National Institutes of Health, leads and coordinates the Federal biomedical research efforts in lupus.

- The NIAMS conducts and supports considerable research on the causes, diagnosis, treatment, and prevention of lupus. The Institute also disseminates information and carries out special educational efforts.

- The NIAMS, in response to findings that certain populations have a higher incidence, prevalence, and mortality rate of systemic lupus, has initiated a Task Force on Lupus in High Risk Populations.

- Task Force members include representation from the Department of Health and Human Services' Office of Minority Health, the Public Health Service Coordinating Committee on Women's Health Issues, the Lupus Foundation of America, The American Lupus Society, minority and majority health professionals and laypersons, and NIAMS program and public information staff.

- The goal of the task force is to develop educational strategies directed to patients, the public, and health professionals that may help improve the outcome of lupus in populations at high risk of developing the disease.

MEMBERS OF THE TASK FORCE ON LUPUS IN HIGH RISK POPULATIONS

Sponsored by the National Institute of
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National Institutes of Health

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FILL-IN-THE BLANKS PRESS RELEASE

FOR IMMEDIATE RELEASE
Date

CONTACT: Name
Telephone Number

(Organization) has joined a nationwide campaign to raise awareness of lupus and its symptoms among black women.

The campaign, "What Black Women Should Know About Lupus," set to begin in National Lupus Awareness Month in October, is intended to raise awareness of lupus and its symptoms among black women and encourage them to see their doctor if they have signs of the disease, said (Name) of (Organization).

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a component of the National Institutes of Health, is urging groups to organize events and programs that will inform black women about lupus. In many cities, organizations are expected to sponsor special events and distribute material at worksites, churches, and other community settings. Locally, (Name) said activities will include (List Activities).

The NIAMS believes that women who think they have lupus should be examined by a doctor and be tested for the disease. Lupus is a serious health problem that mainly affects young women. Although people of all races may get lupus, it has a three times higher incidence, prevalence, and mortality in black women than in white women.

"Many in the black community have never heard of lupus, and it often goes undiagnosed until serious complications arise," said (Local Physician). "If left untreated, the disease may damage the joints, skin, kidneys, lungs, heart or brain." (Local Physician) added that with the correct medicine and taking care of themselves most lupus patients can hold a job, have children, and lead a full life.

# # #

HOW TO WORK WITH THE MEDIA

Local media outlets are always interested in stories with a local twist. They provide numerous opportunities to inform young black women about lupus.

This tipsheet tells you how to use the materials in this kit to get maximum coverage of your local efforts, whether they revolve around National Lupus Awareness Month or continue throughout the year, by working closely with radio and television stations, newspapers, newsletters, and other publications.

Getting Started--The Basics of Working With the Media

1. Develop a List

   The first step is to develop--or update--your list of local press contacts. Try to include representatives from:

   - Radio stations.
   - Television stations, including local network affiliates, independent stations, and cable outlets.
   - Regional news services such as the nearest Associated Press bureau.
   - Daily and weekly newspapers.
   - Community advertisers publications ("shoppers").
   - Publications of civic, service, religious, fraternal, business, and health professional organizations.

   Your most important contacts will be television public service directors, assignment editors, and reporters assigned to cover health and local issues. In addition, business editors can help you publicize worksite activities, and "calendar" editors can announce upcoming events. Talk show hosts and/or their producers are also good media contacts if you want to offer as a guest a spokesperson who is knowledgeable about the topic.

2. Identify Spokespersons

   The next step is to select one or a few media spokespersons. This individual should be very knowledgeable about lupus, such as a local rheumatologist who treats patients with the disease, and should be willing to keep up to date on new developments in the

field. Your spokespersons also should be available and willing to respond to calls from the media.

Some General Tips on Media Contacts

- When talking to reporters and others about your activities, emphasize what is unique and compelling about the campaign. The information in the enclosed factsheet should help.

- Give reporters enough lead time to cover your story--about 1 week for a press release and 2 weeks for a feature story.

- Make brief and concise followup calls after you've sent materials on upcoming events--but never call around deadline times. If you aren't sure when deadlines are, simply ask if the reporter is on deadline and when you should call back.

- If you send your materials to more than one person in an organization, make sure each recipient knows.

- One or two days before a special event, contact the local bureau of a news service to have the event publicized in the "daybook" calendar listing. The daybook is checked daily by print and electronic media outlets. Look for "Bacon's Publicity Checker" in your library for the nearest bureau of the Associated Press, United Press International, or Reuters, Ltd. These are the three major news services used by daily newspapers.

Using the Materials in This Kit

Adapt the press release to meet your needs. Add the fact sheet, the "health watch" article, booklet, and information about your own organization, and you have an informative mailing for the local media.

Print Media

- Distribute the "health watch" article to smaller daily and weekly newspapers and community organization publications; they almost always can use more material.

- Submit some ideas for local stories on lupus in black women to newspaper editors and to freelance health writers and offer your group as an informative source. You may want to have a lupus patient talk to them about the importance of early detection.

- Ask the calendar editors of local newspapers to run a brief announcement of the location, date, and time of your special event.

Radio

- Schedule your organization's key health spokesperson on radio talk shows to discuss the signs and symptoms of lupus. Provide the interviewer with suggested questions.

- Ask all-news radio stations to develop a series of short features on early detection. Offer your assistance in providing background information and contacting experts for interviews.

- Provide announcers with the public service announcements in this kit.

Television

- Meet with television anchors, assignment editors, and health reporters to discuss possible ideas for news features and to provide them with the background materials in this kit.

- Meet with public service directors of television stations, including cable television, to discuss the importance of early detection information to their viewers. Ask for help in producing local public service messages using the early detection theme.

- Arrange to tape a "community calendar" spot for television stations or cable television outlets to promote your special events and activities.

- Schedule television talk show appearances for your organization's spokesperson.

- Encourage producers of television magazine shows to produce segments on early detection.

- Work with public service or public affairs directors to develop on-air editorials about lupus and black women.

THIS KIT CONTAINS facts and information you can use to promote awareness of lupus among black women in your community.

Feel free to adapt the kit to meet your needs. We designed the materials to be copied and distributed widely throughout your local networks. Please let us know what you think of the kit and how your organization observed National Lupus Awareness Month, or how you plan to use the materials at any time during the year. A response card is enclosed for your convenience.

The materials can be used in settings such as health fairs, clinics or hospitals, workplaces, churches, retail outlets, libraries, and recreation centers. Enclosed you will find:

- Memorandum to Colleagues
- Information on NIAMS and the Task Force on Lupus in High Risk Populations
- List of Task Force Members
- Facts About Lupus and Black Women
- Information Booklet--"What Black Women Should Know About Lupus"
- Newsletter Article--"Health Watch: Black Women and Lupus"
- A "fill-in-the blanks" press release
- Ideas on how to work with local media
- PSA's for use by radio announcers
- Suggested activities
- Sources of information on lupus
- List of selected patient education materials
- Poster
- Camera-Ready Artwork: booklet, poster, butterfly logo, stationery
- Response card
- Order form

PUBLIC SERVICE ANNOUNCEMENT COPY (30 SEC.)

Lupus Awareness in Young Black Women

Lupus is a serious health problem that is of special concern to young black women. Although people of all races may get lupus, it is three times more common in black women than in white women. Common signs of lupus are red rash or color change in the face, painful or swollen joints, unexplained fever, chest pain with breathing, unusual loss of hair, sensitivity to the sun, and a low blood count. If you think you have signs of lupus, see a doctor. For a free copy of the booklet "What Black Women Should Know About Lupus," call _____ (local organization phone number).

PUBLIC SERVICE ANNOUNCEMENT COPY (60 SEC.)

Lupus Awareness in Young Black Women

Lupus is a serious health problem that is of special concern to young black women. Although people of all races may get lupus, it is three times more common in black women than in white women. Lupus is hard to diagnose and may mimic other diseases. It may damage the joints, skin, kidneys, lungs, heart, or brain. Common signs of lupus are red rash or color change in the face, painful or swollen joints, unexplained fever, chest pain with breathing, unusual loss of hair, sensitivity to the sun, and a low blood count. Researchers at the National Institutes of Health are studying new ways to treat and, hopefully, prevent lupus. If you think you have signs of lupus, see a doctor. For a free copy of the booklet "What Black Women Should Know About Lupus," call _____ (local organization phone number).

Suggested Activities

Here are examples of things you can do in your community to increase awareness about lupus in black women. There are activities that your organization can do alone or with other groups. These suggestions are to help you plan your programs. Feel free to change or combine the activities to meet your local needs.

LUPUS AWARENESS MONTH

October is Lupus Awareness Month. It is a great time to start or expand lupus education activities.

- Contact your local chapters of the Lupus Foundation of America, Inc., or The American Lupus Society to plan programs or seminars for your organization.
- Get the media in your area to do a story about lupus. Send them the artwork and editorial material from the kit. Give them suggestions of local doctors and lupus patients they can interview.
- Ask a health professional to come talk to your group about lupus. Tell him or her you want to know about symptoms, treatment, and research advances.

COMMUNITY SETTINGS

- Publish lupus information in organization newsletters or magazines, using the reproducible art and article from this kit. Include information about local resources.
- Encourage religious leaders to promote lupus awareness and its potential effects on black families. Duplicate or reprint the booklet, factsheet, and posters from the kit for distribution at churches.
- Put the brochure in the reference section of your library, ask the librarian to distribute copies, and suggest that they use the poster and other materials for a display in October.
- Contact recreation centers about putting on programs or distributing materials.

RETAIL OUTLETS

- Encourage local drug stores to put up the posters and to distribute the factsheets and brochures. Ask the pharmacies to have a special lupus display during Lupus Awareness Month.

- Hold a health fair with other organizations at a shopping mall or office building. Ask the local chapter of the Lupus Foundation of America, Inc., or The American Lupus Society for information on getting things started.

WORKSITES

- Place the posters on office or corridor bulletin boards.

- Reprint the factsheets and artwork to distribute them to your coworkers.

- Hold a brown bag lunch about lupus. Invite a lupus patient and her doctor to discuss their experiences. Borrow from your local library an audiovisual program or video about lupus to show to your brown bag lunch group.

Sources of Information on Lupus

Lupus Foundation of America, Inc. (LFA)
4 Research Place
Suite 180
Rockville, Maryland 20850-3226
(800) 558-0121

The American Lupus Society (TALS)
3914 Del Amo Boulevard
Suite 922
Torrance, California 90503
(800) 331-1802

These organizations, which have chapters around the country, publish booklets and newsletters, and have programs about the causes, symptoms, and treatment of lupus. They also can make medical referrals.

National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892
(301) 496-4484

The National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse (NAMSIC) is a national resource center for information about professional, patient, and public education materials; community demonstration programs; and Federal programs related to rheumatic, musculoskeletal, and skin diseases. The Clearinghouse has developed a data base that collects and disseminates information and materials about lupus. It also has produced Lupus Patient Education Materials: An Annotated Bibliography, which contains 162 citations to educational materials for patients and their families about the symptoms, diagnosis, and treatment of lupus. The bibliography is available for $4.00 from the Clearinghouse.

NIAMS Task Force on Lupus in
High Risk Populations
National Institute of Arthritis and
Musculoskeletal and Skin Diseases (NIAMS)
NIH Publication No. 91-3219
July 1991

What Black Women Should Know About Lupus

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service National Institutes of Health

Prepared by the
NIAMS Task Force on Lupus in High Risk Populations
National Institute of Arthritis and Musculoskeletal and Skin Diseases
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892

The NIAMS, a part of the National Institutes of Health, leads and coordinates the Federal biomedical research effort in lupus.

This booklet is not copyrighted. Readers are encouraged to duplicate and distribute as many copies as needed. Reproducible artwork as well as single copies may be obtained from the NIAMS Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892. The NIAMS welcomes comments on this booklet.

Do You or Someone You Know Have Signs of Lupus?

Lupus is a serious health problem that mainly affects young women. Most people with lupus first get it as teenagers or as young adults. People of all races may get lupus. However, lupus is three times more common in black women than in white women.

What Is Lupus?

Lupus is a disease that can affect many parts of the body. It may affect the joints, the skin, the kidneys, the lungs, the heart, or the brain. In most people only a few of these parts of the body are affected.

In lupus, something goes wrong with the body's immune system and this powerful protective system is no longer able to defend the body against illness. We can think of the immune system as an army within the body with hundreds of soldiers (known as antibodies). They defend the fort or body from attack by germs and viruses. However, the immune system sometimes becomes overactive and goes out of control.

The soldiers (antibodies) attack healthy tissues in the body. This attack causes redness, pain, and swelling (inflammation) in certain parts of the body. The tendency for the immune system to become overactive may run in families.

What Causes Lupus?

We don't know what causes the immune system to become overactive. In some cases, lupus becomes active after exposure to sunlight, infections, or medications.

Is Lupus Catching?

No, lupus is not catching. You can't give it to someone else. It is not a form of cancer. It is not AIDS.

How Serious is Lupus?

Signs of lupus tend to come and go. There are times when the disease quiets down or goes into remission. At other times, lupus flares up or becomes active. Years ago, many people with lupus died. Now with early medical care most people with the disease can lead active, productive, and fulfilling lives.

Signs of Lupus

1. Red rash or color change on face, often in the shape of a butterfly across the bridge of the nose
2. Painful or swollen joints
3. Unexplained fever
4. Chest pain with breathing
5. Unusual loss of hair
6. Pale or purple fingers or toes from cold or stress
7. Sensitivity to the sun
8. Low blood count

These signs are more important when they occur together.

For further information on lupus, see your doctor or health clinic and contact your local chapter of the following organizations:

Lupus Foundation of America, Inc.
4 Research Place
Suite 180
Rockville, Maryland 20850-3226
(301) 670-9292
(800) 558-0121

The American Lupus Society
3914 Del Amo Blvd.
Suite 922
Torrance, California 90503
(213) 542-8891
(800) 331-1802

Is There a Cure for Lupus?

At this point, lupus cannot be cured. However, in many cases, signs of the disease can be relieved. The good news is that with the correct medicine and taking care of themselves most lupus patients can hold a job, have children, and lead a full life.

Outlook

The outlook for lupus patients has greatly improved. Research doctors supported by the National Institutes of Health have learned a great deal about lupus and are studying new ways to treat and, hopefully, prevent the disease. The future holds great promise for improving the health of all Americans who have lupus.

Awareness

Please share this booklet with your family and friends. Someone you know or care about may have lupus.

Are There Different Kinds of Lupus?

There are three types of lupus: lupus that affects certain parts of the body (systemic lupus), lupus mainly of the skin (discoid or cutaneous lupus), and lupus caused by medicine (drug-induced lupus).

Systemic lupus is the most serious form of the disease. Systemic means that it may affect many different parts of the body, such as the joints, skin, kidneys, lungs, heart, or the brain. This type of lupus can be mild to serious. If it is not treated, systemic lupus can cause damage to the organs inside your body.

Discoid and cutaneous lupus mainly affect the skin. The person may have a red rash or a color change of the skin on the face, scalp or other parts of the body.

Lupus caused by a small number of prescription medications is called drug-induced lupus. The person with drug-induced lupus may have the same symptoms as the person with systemic lupus. Usually, when the medicine is stopped, the disease goes away. Drug-induced lupus is usually found in older men and women of all races.

Do Men Get Lupus?

Yes, men get all forms of lupus. However, 9 out of 10 people who have lupus are women.

Does Lupus Run in Families?

Most relatives of lupus patients do not develop the disease, but in some families more than one member gets lupus. If a relative of a lupus patient develops signs of lupus, she or he should see a doctor.

What Are the Signs of Lupus?

The signs of lupus differ from one person to another. Some people have many signs of the disease. Others have just a few. Lupus is hard to diagnose and is often mistaken for other diseases. For this reason, it has often been called the "great imitator."

Common signs of systemic lupus are:

- Red rash or color change on the face, often in the shape of a butterfly across the bridge of the nose
- Painful or swollen joints
- Unexplained fever
- Chest pain with breathing
- Unusual loss of hair
- Pale or purple fingers or toes from cold or stress
- Sensitivity to the sun
- Low blood count

These signs are more important when they occur together.

Other signs of lupus can include mouth sores; unexplained fits or convulsions; hallucinations or depression; repeated miscarriages; and unexplained kidney problems.

Does Sunlight Cause Lupus?

In some people, an attack of lupus may be brought on by being in the sun.

What Should You Do if You Think You Have Lupus?

You should see a doctor or a nurse and be examined and tested for lupus. Many people have lupus for a long time before they find out about it.

How Is Lupus Treated?

The doctor may treat each lupus patient in a different way because the signs of lupus often differ from one person to another. The doctor may give aspirin or similar medicine to treat the fever and the painful, swollen joints. Creams may be prescribed for the rash, and stronger medicines prescribed for more serious problems.

In addition to medicine, lupus patients may need extra rest. However, in spite of their disease, they should try to be as active as possible.

Lupus in High Risk Populations

PLEASE LET US KNOW!

Your comments help us evaluate and improve our public information campaign! Please take a minute to complete this response form and mail to: National Institute of Arthritis and Musculoskeletal and Skin Diseases, Task Force on Lupus in High Risk Populations, Box AMS, 9000 Rockville Pike, Bethesda, MD 20892.

1. Have you used or do you plan to use the following kit materials?

   Facts About Lupus and Black Women

   Newsletter Article - "Health Watch: Black Women and Lupus"

   Information Booklet - "What Black Women Should Know About Lupus"

   Camera-Ready Artwork for the Booklet

   Poster

2. Have you conducted activities or do you plan to conduct activities using the list of "Suggested Activities" enclosed in the kit? YES____ NO____

   If so, please list those activities you have selected.

_____
_____
_____
_____

3. Would you like to receive similar information in the future?
   YES___ NO____

Comments_____
_____
_____
_____

4. We are considering sending out a biannual bulletin to help build the network of community organizations concerned with lupus, especially as it affects black women. Can we describe your activities in such a bulletin? YES___ NO___
   Would you like to be on the mailing list? YES___ NO___

NAME:_____TITLE:_____
ORGANIZATION:_____
ADDRESS:_____
CITY:_____STATE:_____ZIP_____
TELEPHONE:_____FAX:_____